

Yale CANCER CENTER *answers*

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Bereavement Services

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Welcome to Yale Cancer Center Answers with your hosts doctors Francine Foss, Anees Chagpar and Steven Gore. Dr. Foss is a Professor of Medicine in the Section of Medical Oncology at the Yale Cancer Center. Dr. Chagpar is Associate Professor of Surgical Oncology and Director of the Breast Center at Smilow Cancer Hospital and Dr. Gore is Director of Hematological Malignancies at Smilow. Yale Cancer Center Answers features weekly conversations about the research diagnosis and treatment of cancer and if you would like to join the conversation, you could submit questions and comments to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. This week you will hear a conversation about grief and bereavement with Bonnie Indeck and Andrea Lucibello. Bonnie is Manager of Oncology Social Work at Smilow Cancer Hospital and Andrea is a Social Worker and Coordinator of Bereavement Services at Yale, New Haven. Here is Dr. Steven Gore.

Gore Bereavement Services, tell me about that is. Obviously it is such an important aspect, especially when we are talking about cancer and obviously it is not limited to cancer. What do bereavement services consist of?

Lucibello Our Bereavement Services are actually part of the Palliative Care Team. I am a member of the Palliative Care Team and the goal for Bereavement Services is to provide support and education to family members after the death of a loved one.

Gore How does that work? Do you get referred to patients who are having trouble or do you find out about all the patients who have had a loss or all the families who have had a loss?

Lucibello It works in many different ways. Staff will refer families to me and I will contact them. We also get folks who are interested in bereavement services and will contact us from the community. The support services that we offer are bereavement seminars where we offer folks education on grief reactions. We also offer bereavement support groups. We do telephone support and one-to-one meetings. We offer a holiday program called Hope for the Holidays as well as our annual memorial service.

Gore Obviously anybody who has a loss is going to be doing some grieving, how do I know if I need a bereavement service? How do I know if my grieving is out of the ordinary or extreme?

Lucibello Grief is actually a natural response to loss and grief is universal, but every individual is different, and how they experience grief. It is unique to the individual, and also grief is not a linear process and so that is what we do try to teach folks and a lot of times when I am working with folks, people will initially ask, how long is this going to last, how long am I going to be feeling like this? And what I tell people is that it can be a lifelong journey; however, with support and education and also learning how to reinvest or rebuild a life after the loss of a loved one, the bereavement and the grief is not going to be as sharp or as painful as it was when the death occurred.

Gore So you are available if I am feeling uncomfortable and it does not matter if I have been uncomfortable for a week or two months or a year?

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- Lucibello It could be a year. Sometimes it could even be two years. When a person dies or loses a loved one, their world is thrown off balance, much like a mobile in a baby's crib, if it loses a piece, it is just thrown off balance and so for the first few weeks, people are experiencing shock, disbelief; it is very hard to wrap your mind around what has just happened, the loss and the death of a loved one, but then as bereavement goes on and time goes on, the mind, the psyche, the emotional state starts to realize, this is not going to change, this is very real, and so grief reactions can come in many different ways, folks can experience physical distress, grief might affect people through stomach distress, headaches, chest pains, chest tightness. There are also emotional reactions to grief besides sadness. It could be anger, guilt. A lot of people will tell me also lack of joy, lack of being able to experience joy and being very frightened that they will never experience joy again.
- Gore Do you work with psychiatrists or other mental health professionals outside of social work in terms of medication or is that not really necessary for most patients?
- Lucibello For most people they probably will not need psychiatric medications; however, there is a group of folks who may experience complicated grief, and when someone experiences complicated grief, a lot of times some of the risk factors may be that they have already been diagnosed with a psychiatric illness. They may have had a history or currently have difficulties with substance abuse, they might have had a conflicted relationship with their loved one. They might even have a physical illness. So, what we want to be able to do is identify those who may be at risk for complicated grief and then at that point, I would refer out.
- Gore I see. Let's take a generic case, I have recently lost a loved one, I feel like I do not like the way I am feeling, how am I going to find you, what are you going to do, I am a little afraid, I have never really been in therapy or anything, I do not work with people like you, and I am a guy and so I am a little afraid to admit that I am crying a lot, let us just say.
- Lucibello Yeah, absolutely. First we will talk a little bit about what are the life stressors someone might be going through.
- Gore Sure.
- Lucibello Because that is another factor, if someone is having difficulties with health or unemployment or even job stressors, that is going to impact on grief and where you in your life cycle is also going to affect grief, so if someone who is 20 comes to me and says that they have lost a parent, it is going to be a very different experience than someone who is 50 and whose parent has died. We are also going to look at your life experience as far as who taught you how to mourn, who taught you how to grieve in your family. You mentioned tears as a man, and a lot of gentlemen that I work with have been taught they should not cry around grief and they are very uncomfortable with it. There are times when they will say to me, I am afraid to start because if I start I am afraid it is going to become a habit. So, we are trying to reframe some lessons that were learned earlier in life and then also the relationship that the person had with the person who died, that has also got an impact on the bereavement experience.

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Gore So is this mostly one-on-one work, you mentioned you have some support groups.

Lucibello We do offer support groups and what we like to have happen is that folks will come to a two-week bereavement seminar where we are teaching about natural grief reactions and then we are also teaching folks some of the skills we will be teaching them in the bereavement support group for the next seven weeks, so we have folks start for two weeks, so that when we do start the group, everybody is on the same page.

Gore Is it once a week for two weeks, the seminar?

Lucibello Once a week for two weeks, and then they will join us for a seven-week seminar where they will be learning skills where we are looking at support in people's lives, activities. We are also looking at how people are rebuilding and reinvesting their life because when people lose a loved one and again depending upon the loved one, they may be taking on new roles, so if a person loses their spouse for example, they may become a single parent. They may have to learn the finances, how to do the financial management of the house. They might have to negotiate home repairs, activities that they were not used to doing, so we help folks make plans for these activities, any support we can give, and then also the support of the group, because the other piece is that folks learn that they are not alone in their grief and they learn and share resources with each other.

Gore So everyone has started at the same time in this group.

Lucibello Yes, it is a close-ended group.

Gore Got it, so everyone is a newbie and they all meet each other. How big is the group?

Lucibello It ranges. It could be anywhere from 5 to 8, maybe 10 people sometimes.

Gore And a variety of ages, I imagine.

Lucibello Yes and we try to organize the group around like losses, so that folks can relate. It might be a widows and widowers support group.

Gore So it would be unusual to have, what you said about maybe a young adult who has lost a parent as well as the 50-year-old who is losing the parent, they would not be in the same group most likely.

Lucibello No, it could be adults.

Gore And that will be parental loss.

Lucibello Yes, that is right, exactly.

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- Gore Because I would think that there would be some benefit to having the older person who has had a different life experience being able to share with the younger person. It is not my area obviously.
- Indeck You are absolutely right that sometimes you can learn a lot from each other and that is a benefit of support groups. You see that somebody shares some information that for whatever reason you identify with, it clicks with you and it really helps you to put things into place. So it is important to share with others who are going through similar situations.
- Gore What happens at the end of the seven weeks?
- Lucibello Generally, people will become friends and become almost a natural support if you will, a natural support network. They get together outside of group, and are supportive to each other.
- Gore That is allowed?
- Lucibello Yes.
- Gore And do people have follow-up with you as well, are most people pretty functional at the end of the seven weeks?
- Lucibello Yeah, certainly we are available. I am available if folks, as they go along, have questions or find that they may be going through a hard time, but by the end of seven weeks, people are realizing, okay, what I am going through is normal. There is nothing abnormal about what I am experiencing and there is nothing wrong with me and are able to continue on.
- Indeck Some of the questions we get may be, I am all alone in this, you do not understand, nobody understands me. Many times people feel like they are the only ones that have suffered a loss. And while the loss, as Andrea said, is unique to that person, people can identify with what that person may feel, so listening to others is very helpful, or just having a one-on-one with Andrea can be extremely helpful to put things into place for them, to re-center themselves.
- Gore Personally, I lost my father at a very young age. I was 16 and I always thought of myself as sort of my one peer who was parentless who did not have a father and that may be an extraordinary case and I am kind of embarrassed to say that over the years as other people lost their parents, I took a little solace in that, you feel guilty that way, but now other people know this too.
- Indeck Right, and there are all sorts of feelings that happen, no matter how old you are, including the fact that when you lose your last surviving parent, many people will say, I am an orphan now.
- Gore Yes, I have heard that a lot.

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Indeck You could be a 60-year-old orphan, but that is the way it feels because your parents have started you, you have things in common with them, they know your history like nobody else, and they love you unconditionally, so you have to help people to realize that your parents may still be with you without being there physically.

Gore Sure.

Indeck And how can you make those memories last, how can you identify, what pictures can you put up that are meaningful to you? Often times, people will say, I have turned into my mother, now I know because I have heard her and I am saying the same thing she is and for some people that is extremely comforting.

Gore This is a really important conversation and we are going to continue it in a minute, but right now, we need to take a short break for a medical minute. Please stay tuned to learn more information about Bereavement Services with Bonnie and Andrea.

Medical Minute

It is estimated that over 200,000 men in the United States will be diagnosed with prostate cancer this year with almost 3000 of these diagnoses here in Connecticut, one in six American men will develop prostate cancer in the course of his lifetime. Major advances in the detection and treatment of prostate cancer have dramatically decreased the number of men who die from this disease. Screening for prostate cancer can be performed quickly and easily in a physician's office using two simple tests, a physical exam and a blood test. Clinical trials are currently underway at federally designated comprehensive cancer centers, such as Yale Cancer Center and at Smilow Cancer Hospital at Yale-New Haven to test innovative new treatments for prostate cancer. The Artemis Machine is a new technology being used at Smilow that enables targeted biopsies to be performed as opposed to removing multiple cores from the prostate for examination which may not be necessary. This has been a medical minute brought to you as a public service by Yale Cancer Center and Smilow Cancer Hospital at Yale-New Haven. More information is available at yalecancercenter.org. You are listening to the WNPR, Connecticut's public media source for news and ideas.

Gore Welcome back to Yale Cancer Center Answers. This is Dr. Steven Gore and I am joined tonight by my guests, Bonnie Indeck and Andrea Lucibello. We are discussing bereavement and bereavement services. One thing I wanted to ask you before the break was whether you have services that help engage familial support, say of the grieving person, the spouse, sometimes I think they do not know what to do to help their partner whether it is the spouse or partner.

Lucibello Even friends a lot of times in the groups will be talking about how a lot of times they do not hear from family or friends and it can be lonely. So what I encourage folks to do, spouses, friends of people who are grieving is to reach out and listen. I think people feel that they might have to fix

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things, and with grief, there is no fixing but listening can be an incredible gift that they give to their loved one. In addition, people can send cards, invite folks to events that you used to invite them to, and allow your loved one to cry if they need to cry and to not be afraid of that.

Gore Yeah.

Lucibello Just to be there, just to be present and to listen is a huge gift to give to someone who is grieving.

Gore So often people want to make things better and whether they bring in some theological thing saying, he is an angel now, whatever this is, or he will always be there, and it seems to me that that is not always what the grieving person wants to hear. They do not really want to hear anything to make it better, it seems to me, they just want to say what they are feeling.

Lucibello Right, and a lot of times that can be experienced as invalidating of the grief too.

Gore I can imagine.

Indeck And typically clichés do not work. So, you are going to be okay in a month, do not worry, you will get through this, you will meet somebody else or you have another child.

Gore That is a horrible one.

Indeck They are all pretty horrible actually to the person who is grieving.

Gore Yeah.

Indeck But you are absolutely right, so what Andrea says about just pulling up a chair, listening, having a shoulder that the person can cry on, inviting them out, continuing to reach out is really the most beneficial.

Gore And is the general question, how are you or how are you feeling, what do you recommend, just an open ended question?

Lucibello Sure, that will work.

Gore How are you doing?

Indeck Right and if the person wants to talk, they will talk and if they do not, they won't.

Gore Leave them alone.

Indeck You got it, do not constantly push, but remember to ask occasionally. Because otherwise people may feel alone as well. They do not care, they never ask me, but that does not mean that the

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person wants to talk all the time. Sometimes they just want somebody to sit with them, but more often than not people will talk and they will tell you exactly what it is they are feeling and how much they miss their loved one and that can be so helpful just to know that there is somebody listening.

Gore I liked what you said about invite them over and so on. I have heard so often when people have been involved as a couple in a relationship that all of a sudden they are not going out to dinner, they are no longer invited to the theater and they feel left out.

Lucibello Isolating, yeah.

Indeck Right, and I think we are a couple society and if you have lost a spouse and all of a sudden you are a third or a fifth wheel, people read that, and so they do not invite you sometimes and sometimes people are threatened by that, who knows what is in some people's minds so they just stop inviting. And if you do not want to invite somebody to a show for instance because in the beginning that would be really hard to do, invite them to come over for a cup of coffee or see if you can go to their house for a cup of coffee, something of that nature to just slowly bring the person back into life again because as Andrea alluded to, the person who is grieving has to reinvest themselves in life and in the beginning, that feels extremely difficult. It is a very heavy load, you still have all the emotional stuff going on with the person you have lost in way and now you are saying put that on hold and I have to meet new people and do new things, I am not ready. So reinvesting can be difficult.

Gore Yeah, makes sense. What about the role of pastoral care or religious rituals or religious communities or faith communities if people have them? What if people do not have them?

Lucibello We talk about rituals and rituals can be as creative as what the individual wants them to be. They are very important around holidays, special days, anniversaries, birthdays, and they can look at it in many different ways, so I have had some folks celebrate birthdays with an actual party where they will actually have a cake for the person. Sometimes, they honor the person with a special food, that might happen a lot at holidays, sometimes also people buy a gift, the money that they would use to buy a gift for their loved one, they would buy the gift and then donate it perhaps to a loved one's special interest, something like that.

Indeck And sometimes people want to make new traditions for the first year following the death. So Thanksgiving when everybody used to get together they say, you know I am not ready for that this year, let's go out to dinner, next year we will continue it together at home, but spiritual care is an extremely important part of bereavement and I think chaplains play a very large role in this and it is helpful when somebody does have a belief system, but if they do not, I think that there are people who are spiritual who may not be religious.

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- Gore Sure. So how do we reach out to them, I mean how do they get engaged with that, do you have any thoughts about that?
- Lucibello I am just thinking even within the group aspect or even when you are doing one-to-one work it becomes a sacred space. I always call it that and I think that sense of community, the sense that you are not alone, connects with the spiritual piece and bringing people in.
- Gore It makes a lot of sense because whenever you talk about these things that are so private, it does have a certain sanctity I think and people do feel that if I have been in situations like that, they feel very connected.
- Lucibello And the importance of being a safe space too where the feelings can be brought out, whatever those feelings might be.
- Gore How do you do that? These people do not know each other when they come to the group. How do you get them there?
- Lucibello As people share their stories, they hear the commonalities, they are respectful to the differences but also the feelings that people are expressing, the tears that people are expressing and I think it opens the heart and I think that is how the space is created. They create the space too.
- Indeck Andrea is a certified grief specialist, so she has the skill of being able to do that. She has run many groups and there is a skill in being a group facilitator and Andrea has it.
- Gore I would think so. Great, we are very fortunate to have you. It has got to take a toll dealing with people with loss all the time, how do you feel about that?
- Lucibello People comment about that, you go to a party and you tell them what you do for a living.
- Gore Wow, what do you do for fun?
- Lucibello What I always tell folks is that it is the healing process that brings hope. When you meet with folks and you see how the healing takes place and sometimes it is one step at a time, but there is hope and as long as there is hope, for me, it is wonderful, it energizes.
- Gore I can totally relate because of course people come to me in my role as a leukemia physician and ask me the same, how can you deal with that since so many people will die of leukemia, although fortunately, we are curing many more than we used to, and I feel that dealing with the dying process and preparing the patient and their family for it to me that is among the most highly privileged things that I do as a physician and it is not always easy but that is a very sacred place for me to be.

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Lucibello That's right.

Indeck You are absolutely right. A lot of this work gives us opportunities that we are so lucky to have because not many do.

Gore We are privileged.

Indeck It is a privilege, it really is and it is an honor to be able to help people with some of this very challenging work and you have a very hard job and you do it quite well, so people are very lucky to have you.

Gore Well, thank you. I think one of the things that I am very proud of at Smilow and of course, I have spent 26 years at another equally fine institution, I do think that the caring environment and culture at Smilow is spectacular and I am very proud of it. I have noticed that already, I cannot take credit for it, and I think that having things like bereavement services and qualified grief counselors that is obviously part of it, and the whole palliative care thing, this is really a terrific thing to have for our patients and their families. Do families tend to stay in touch with you, it is probably all over the board, some yes, some no.

Lucibello Some yes, some no, but it is always wonderful when you meet them in the community, we are happy to see each other and a lot of times they will continue to talk about how they are doing, what they have been doing, how life has changed.

Indeck I got a card just today from somebody saying, I cannot believe but it is five years since I lost my husband, and still wrote a lovely card updating me on everything that is going on with her family and so I think people do connect and build relationships and keep in touch.

Gore Yeah, I love that myself.

Indeck Yeah, it is great.

Gore Seeing the kids growing up. Tell me about the annual memorial service.

Indeck We do have a memorial service that is for anybody who has died at the hospital and we invite families and friends to come and we typically have a couple of family members talk a little bit about their experience, but it is a time where we do some rituals and allow people to come back together again with some caregivers and connect and thank and follow-up and see how things are. It is a very healing time. We wait a period of time if you have just lost someone you will not be necessarily invited to this year's, we may wait till next year because we want you to be past the very acute phase of the first month or so, but then we will ask you to come and share your stories and it has been a time that has been very rewarding for social workers to be at, to help families afterwards to catch up, to hear how they are doing and know that life does go on, so it is wonderful.

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- Gore It sounds like a really special time.
- Indeck It is.
- Gore Do people come back in subsequent years or is this kind of a one year anniversary type of thing?
- Indeck Yeah, pretty much once a year, sometimes somebody may come for two, but we do some outreach to the families of those who have passed away in recent months.
- Gore At my previous cancer center, they had a similar thing that was sort of an ongoing yearly thing where people would come from even 14 or 15 years, a different flavor.
- Indeck Yeah.
- Gore And that was also very special.
- Indeck And I think one of the most spectacular things we do is we do a lot of memorial services on the units for staff. Because staff feel the grief as well.
- Gore Good point.
- Indeck I know we have not focused on that today, but we want an opportunity for staff to talk about people who they have lost, who they have loved. We have a lot of compassionate caregivers and it is really wonderful when they have the opportunity to touch base to see how they have touched the lives of so many. And that typically is co-facilitated by social work and spiritual care on the units.
- Gore That is great. Do you guys work with Connecticut Hospice at all or any other hospice organizations or is separate?
- Indeck We always collaborate but when it comes to bereavement, hospice has their own programs as we do but we would collaborate absolutely.

Bonnie Indeck is Manager of Oncology Social Work at Smilow Cancer Hospital and Andrea Lucibello is a Social Worker and Coordinator of Bereavement Services at Yale-New Haven. We invite you to share your questions and comments, you can send them to canceranswers@yale.edu or you can leave a voicemail message at 888-234-4YCC. As an additional resource, archived programs are available in both audio and written format at yalecancercenter.org. I am Bruce Barber hoping you will join us again next Sunday evening at 6:00 for another edition of Yale Cancer Center Answers here on WNPR, Connecticut's Public Media Source for news and ideas.